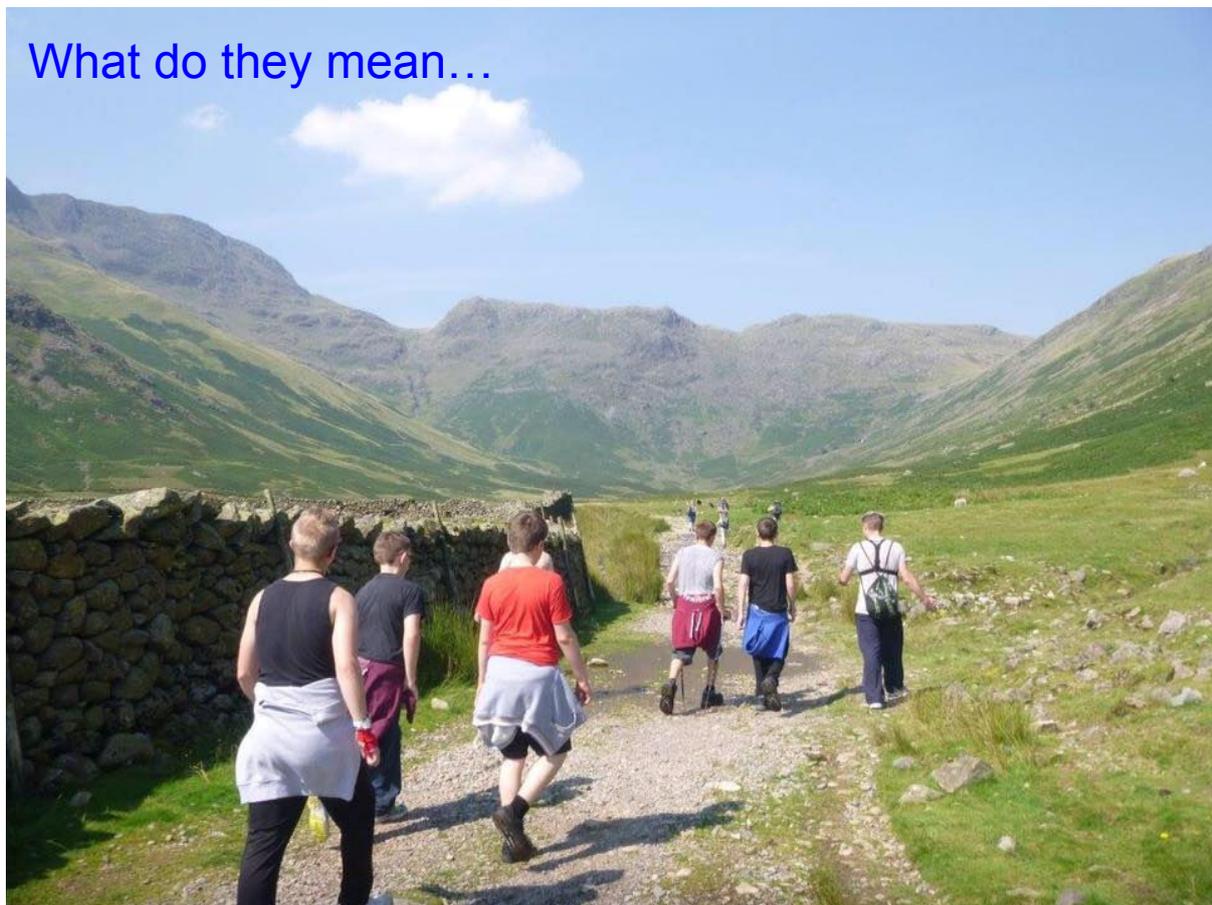




NICE Guidelines

What do they mean...



Contents

Introduction.....	3
Key information for parents and carers.....	4-5
Key points to NICE Guidelines.....	6
Nice Guidelines ASD Pathway.....	7-16
- General Principles for Children and Young People with Autism...	
- Recognition, Referral and Diagnosis.....	
- Recognising possible Autism.....	
- Referral of Children or young person with possible Autism.....	
- Deciding on assessment for possible Autism.....	
- The Autism Diagnostic Assessment	
- Diagnosing Autism in Children and Young People	
- Management and Support	
- Interventions for Behaviour that Challenges	
What should be included in an Autism Diagnostic Assessment?	17
The Guidance – Autism spectrum disorder in under 19s: recognition, referral and diagnosis (September 2011).....	18-31
- 1.1 Local pathway for recognition, referral and diagnostic assessment of possible autism	
- 1.2 Recognising children and young people with possible autism	
- 1.3 Referring children and young people to the autism team	
- 1.4 After referral to the autism team	
- 1.5 Autism diagnostic assessment for children and young people	
- 1.6 After the autism diagnostic assessment	
- 1.7 Medical investigations	
- 1.8 Communicating the results from the autism diagnostic assessment	
- 1.9 Information and support for families and carers	
The Guidance (Recommendations) – Autism spectrum disorder in under 19s: support and management.....	32-43
- 1.1 General principles of care	
- 1.2 Families and carers	
- 1.3 Specific interventions for the core features of autism	
- 1.4 Interventions for behaviour that challenges	
- 1.5 Interventions for life skills	
- 1.6 Interventions for autism that should not be used	
- 1.7 Interventions for coexisting problems	
- 1.8 Transition to adult services	
NICE Guidelines have issued some ‘Do Not’s for children and young people with Autism.....	44
How ASD Helping Hands can assist with the implementation of NICE guidelines....	45
Recommendations.....	46-48

The NICE guidelines are for anyone who is a parent or carer of a child or young person who may have autism or the young person themselves who may have autism. The advice in the NICE guideline covers

- The signs of Autism
- How Autism should be diagnosed in children and young people

Autism

People with autism have difficulties with social situations, with to-and-fro communication, and often with their behaviour. This information uses the word autism, but there are other terms that different people prefer to use – for example, autism spectrum disorder, autistic spectrum condition, autistic spectrum difference and neuro-diversity.

If there is concern that a child or young person may have a problem with development or behaviour, healthcare professionals look for clues as to what the problem might be.

The signs that might suggest autism include problems with speech (not speaking as well as would be expected, not speaking at all or unusual-sounding speech), not talking much, talking only about things they are interested in, or repeating specific words or phrases.

They also look for problems understanding and responding to other people's facial expressions, body language or feelings. Other signs include disliking getting physically close to people, or not knowing how close they can get to other people. Children with ASD may have little imagination.

They have difficulties playing with other children and may prefer to be alone. They may react strongly to certain smells or sounds, or to any change in their routine. Some children have unusual repetitive hand, finger or body movements.

These signs can alert healthcare and other professionals that a child or young person may have autism. However, a child may show different signs, or different signs at different ages, and some signs may have another explanation.

Key information for parents and carers

Initial Concerns – Questions to ask GP/Other Health professionals

- My child seems to be doing quite well for his/her age – why do you think he/she may have autism?
- Can you tell me more about the signs of autism?
- Could my child have a condition other than autism?
- Why have the signs of possible autism not been noticed until now?
- Why is it important for my child to be assessed for autism now?

Who might see my child in the Autism Team?

The autism team may include the following professionals:

- paediatrician
- child and adolescent psychiatrist
- clinical or educational psychologist
- speech and language therapist
- occupational therapist
- Paediatric neurologist.

Members of the autism team should be good at communicating with children and young people who may have autism.

Important questions to ask when going through the Diagnostic Process

- Can you tell me about what the members of the autism team do?
- Please give me more details about my child's assessment for autism.
- Will my child need any other kinds of assessments?
- Who will do the assessments? Where will they be carried out? Will my child need to go into hospital?

- How long will we have to wait to find out about the results and how will we be told about them?
- Why does my child need a physical examination?
- Will my child have to have a blood test?
- Will it be possible to say for definite if my child has autism?

If your child is diagnosed with autism

NICE is developing another guideline that explains how children and young people with Autism should be helped in the NHS.

You should be offered another appointment with a member of the autism team within 6 weeks of the end of the assessment so you can talk more and ask any questions you may have.

They should explain more about autism and how it might affect your child.

You should also be given information about the support you and your child can get in your local area. For example, you may be given contact details for support groups that can give you the opportunity to meet other families with experience of autism, and advice about where to find out about welfare benefits and other services that are available. Your child's healthcare professional should also talk to you about the possibility of future children having autism.

If the diagnosis is uncertain

Sometimes there can be uncertainties when diagnosing autism. The autism team may offer to see your child again or they may offer to refer your child to another team that can help, for example an autism team in specialist care.

If your child does not have autism

Your healthcare professional may offer to refer you to other specialists (for example, child health services or child and adolescent mental health services, also known as CAMHS), if they think they may be able to help.

Key points to the NICE Guidelines

Patient Centred Care – Treatment and care should take into account the needs and preferences of children, young people and those who care for them. Children and young people with autism and their families and carers should have the **opportunity to make informed decisions** about their care and treatment in **partnership with their healthcare professionals**.

- Good communication between healthcare professionals and children and young people is essential
- Families and carers should be given the information and support they need
- Care of young people in transition between paediatric and adult services should be planned and managed – see Department of Health’s ‘Transition: getting it right for young people’

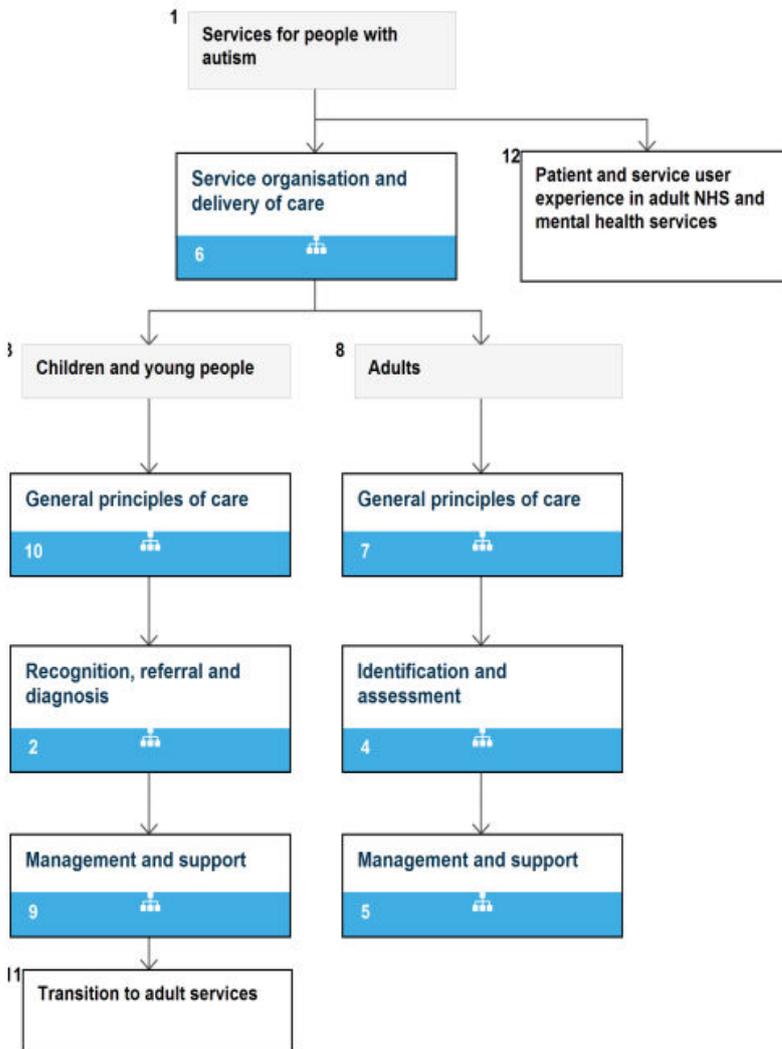
Key issues

- **Capacity to make decisions (See Mental Capacity Act)**
- **Under 16 (see Department of Health’s ‘seeking consent: working with children’)**

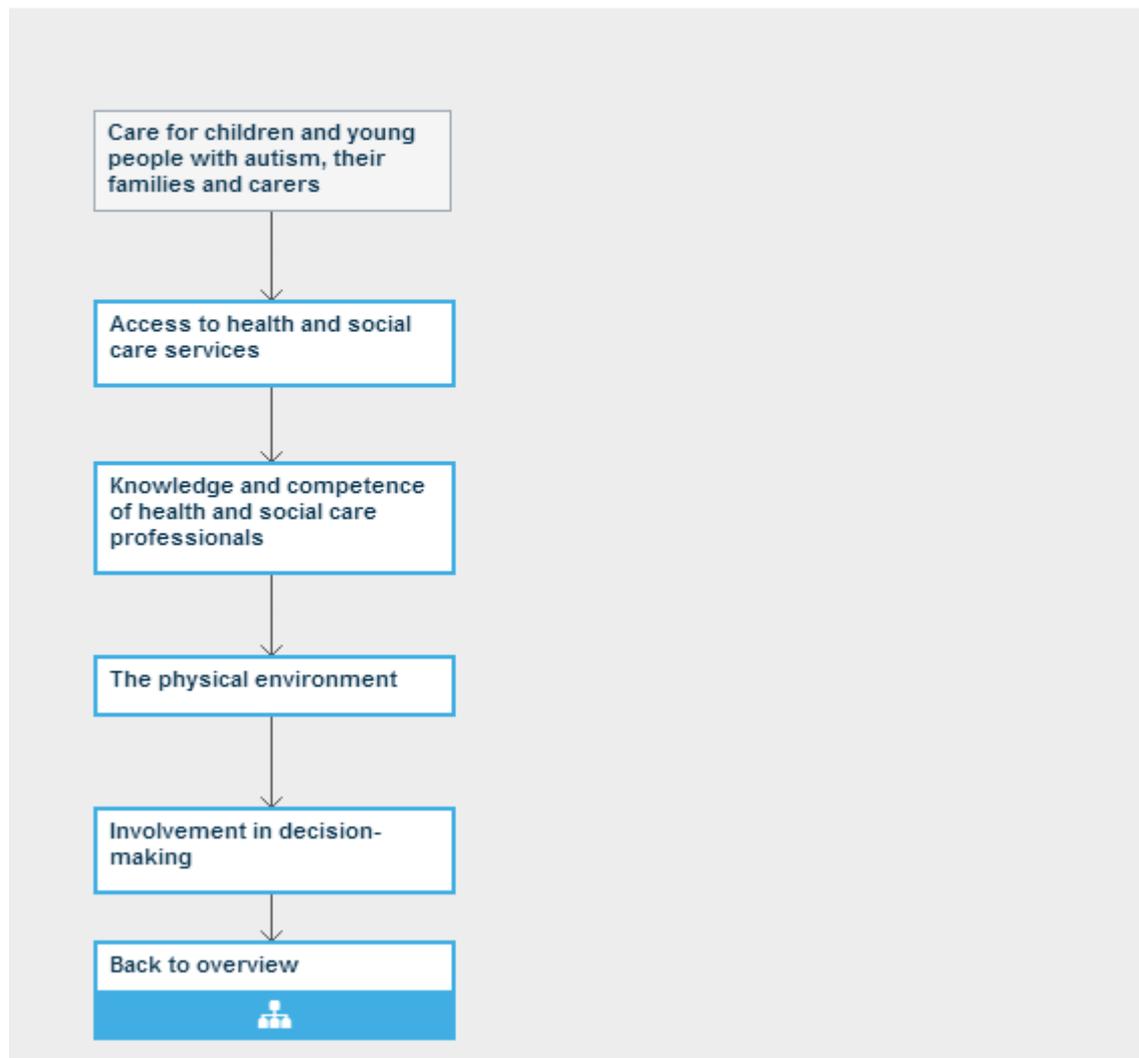
Norfolk has developed its own local ASD Pathway in line with the NICE guidelines however these next pages show you the full extent of the NICE guidelines ASD Pathway

Autism spectrum disorder overview

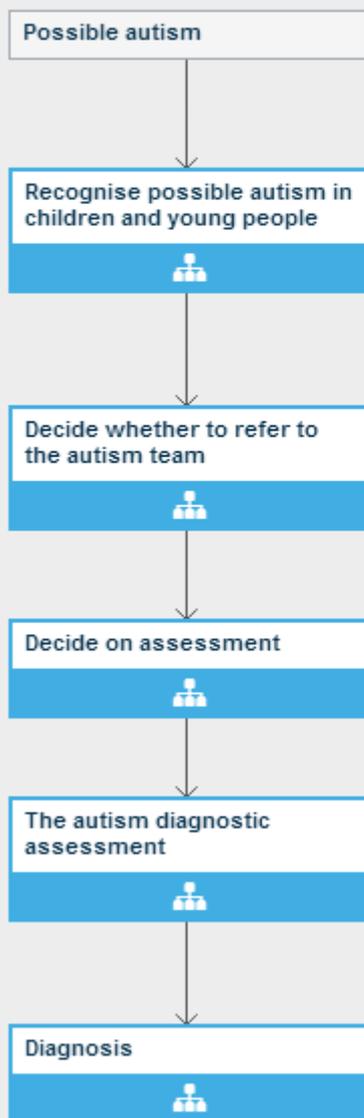
NICE Pathways



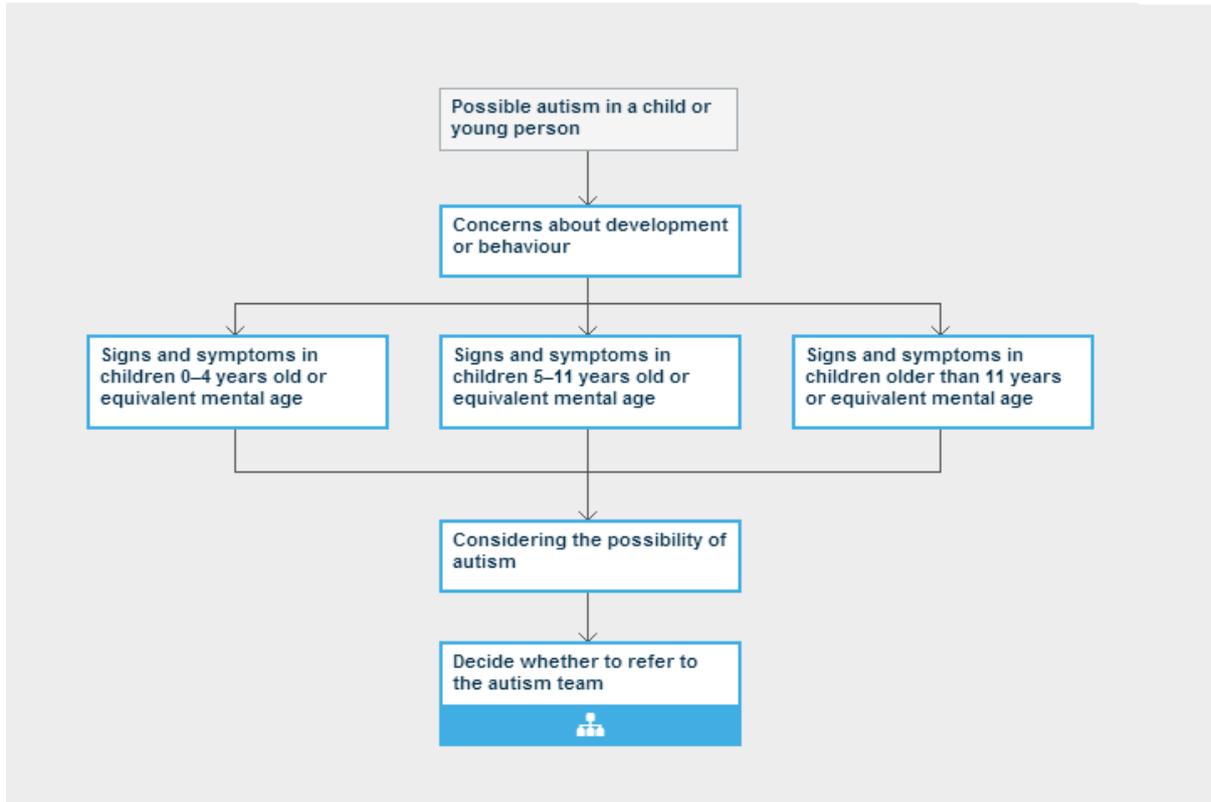
General principles of care for children and young people with autism



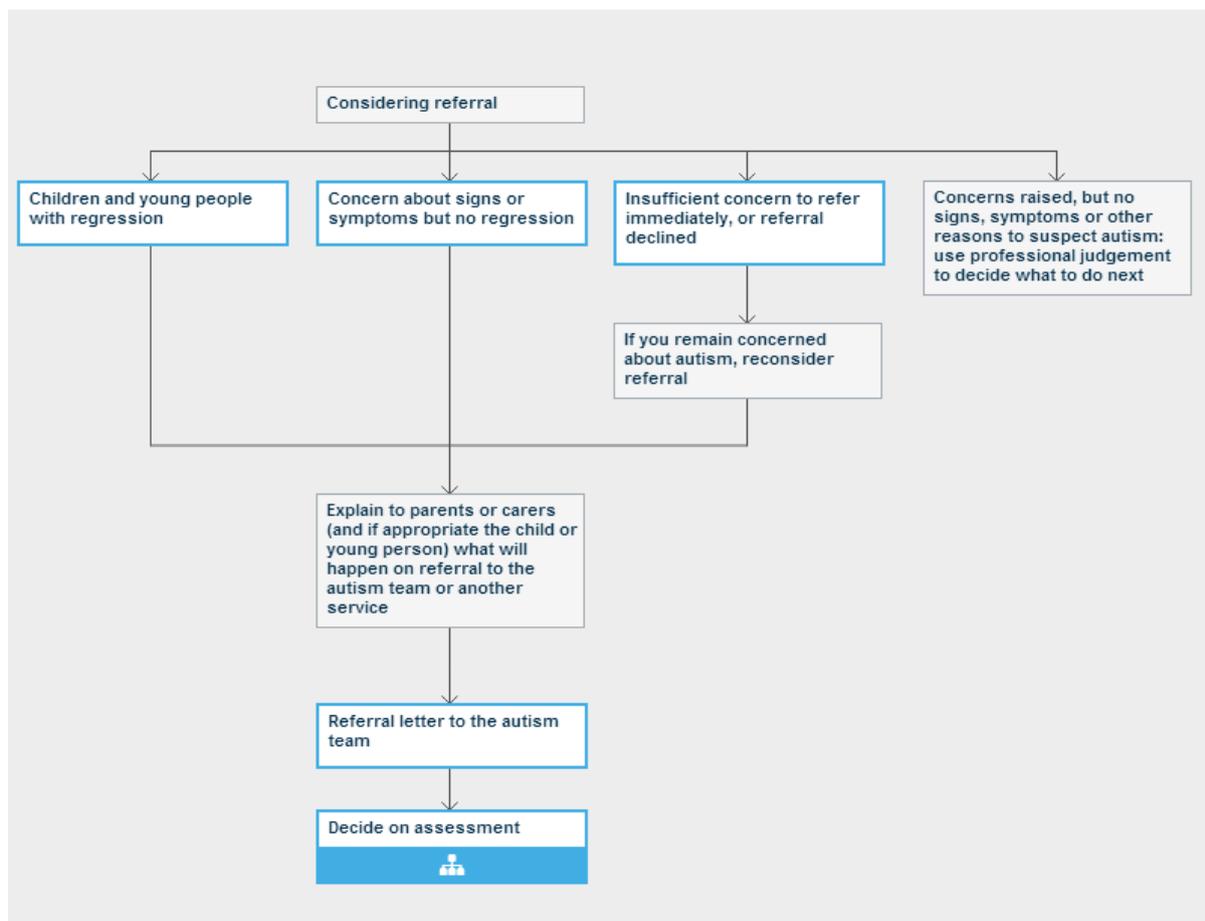
Recognition, referral and diagnosis of autism in children and young people



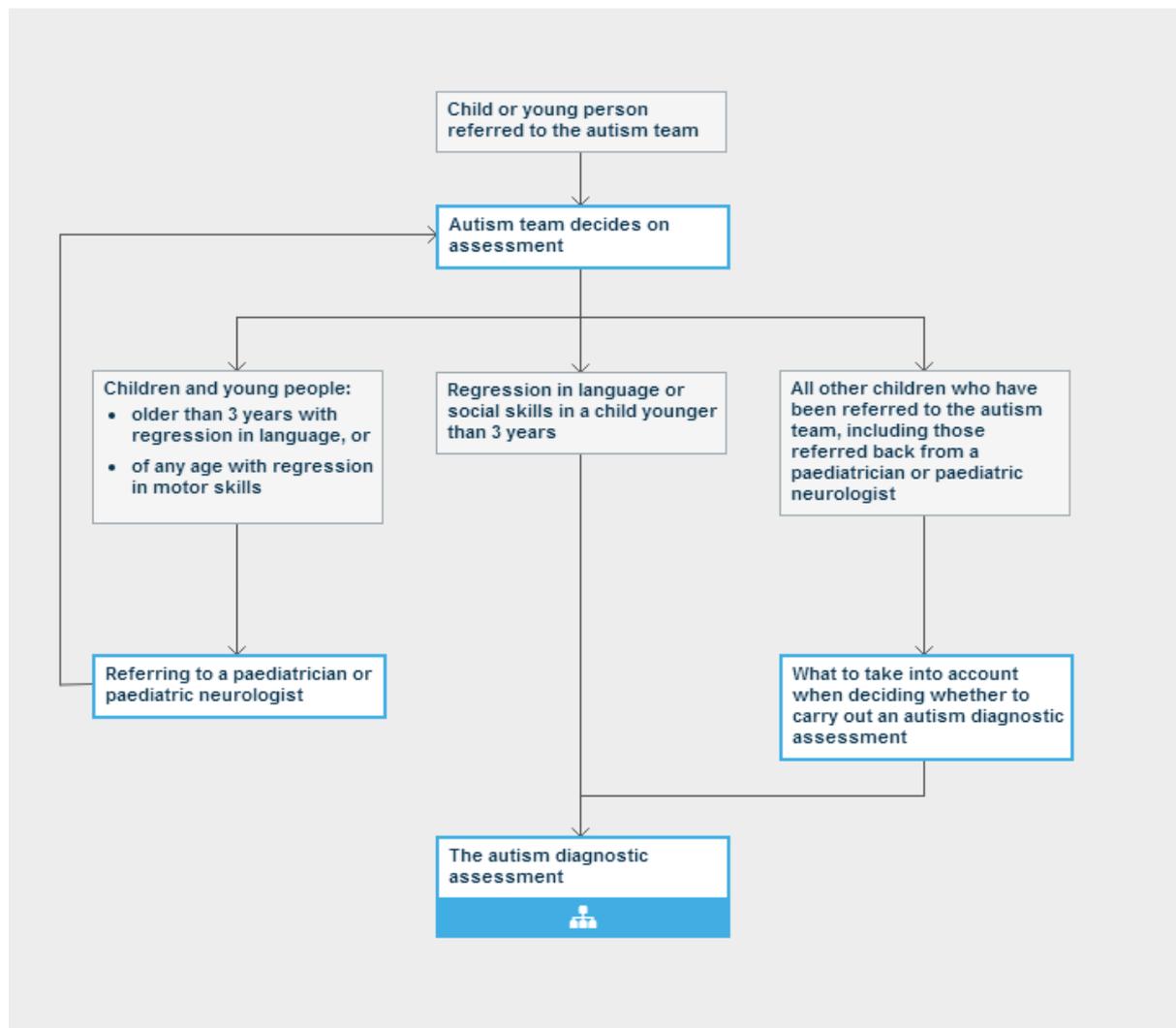
Recognising possible autism in children and young people



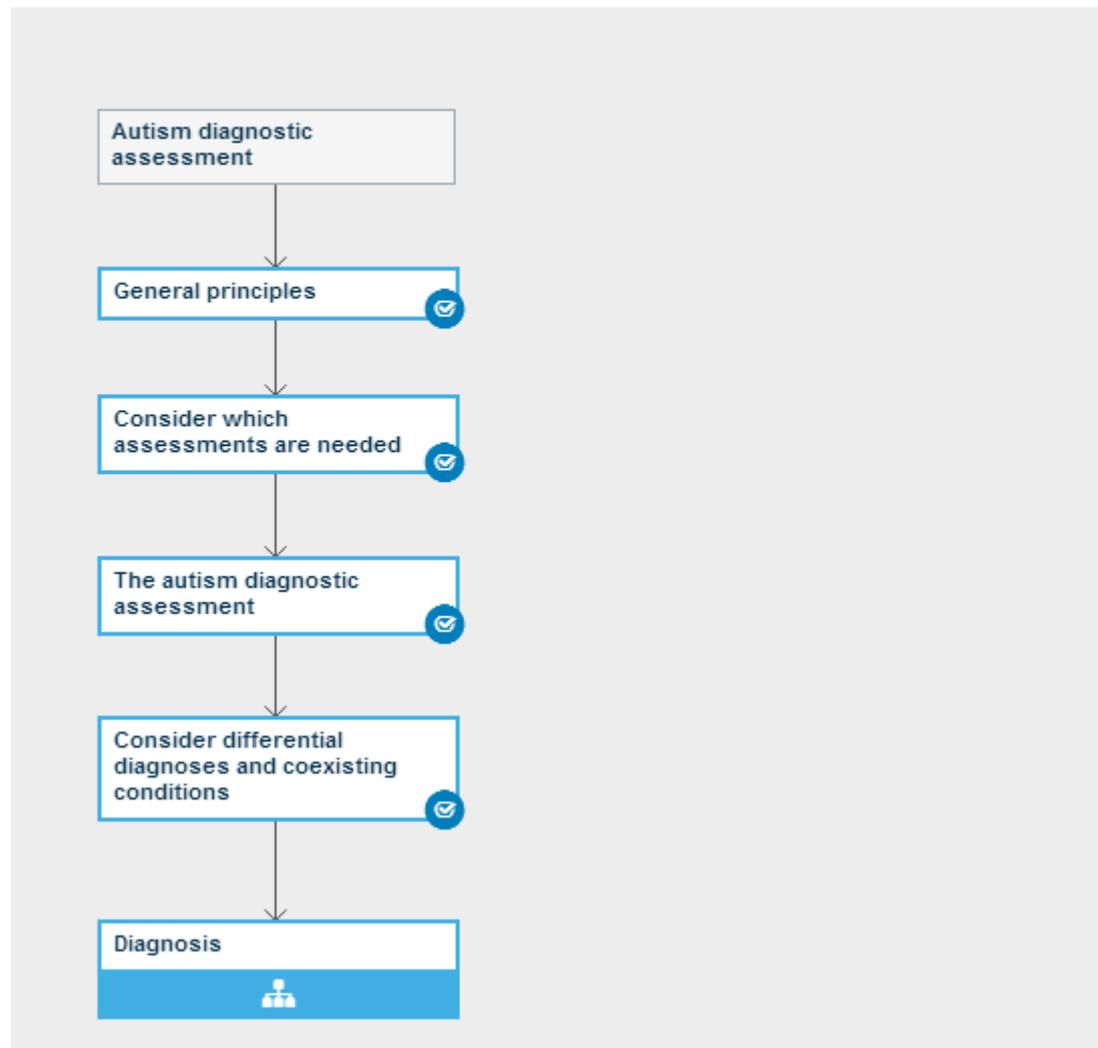
Referral of children and young people with possible autism



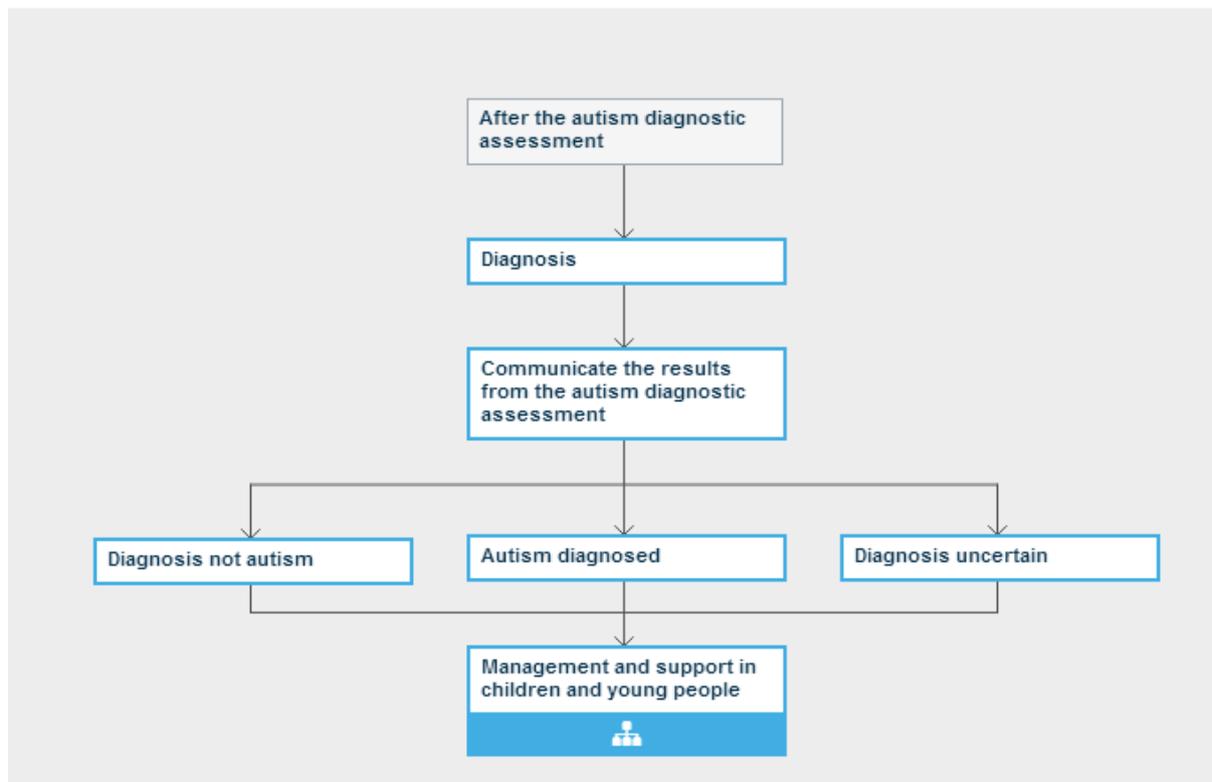
Deciding on assessment for possible autism in children and young people



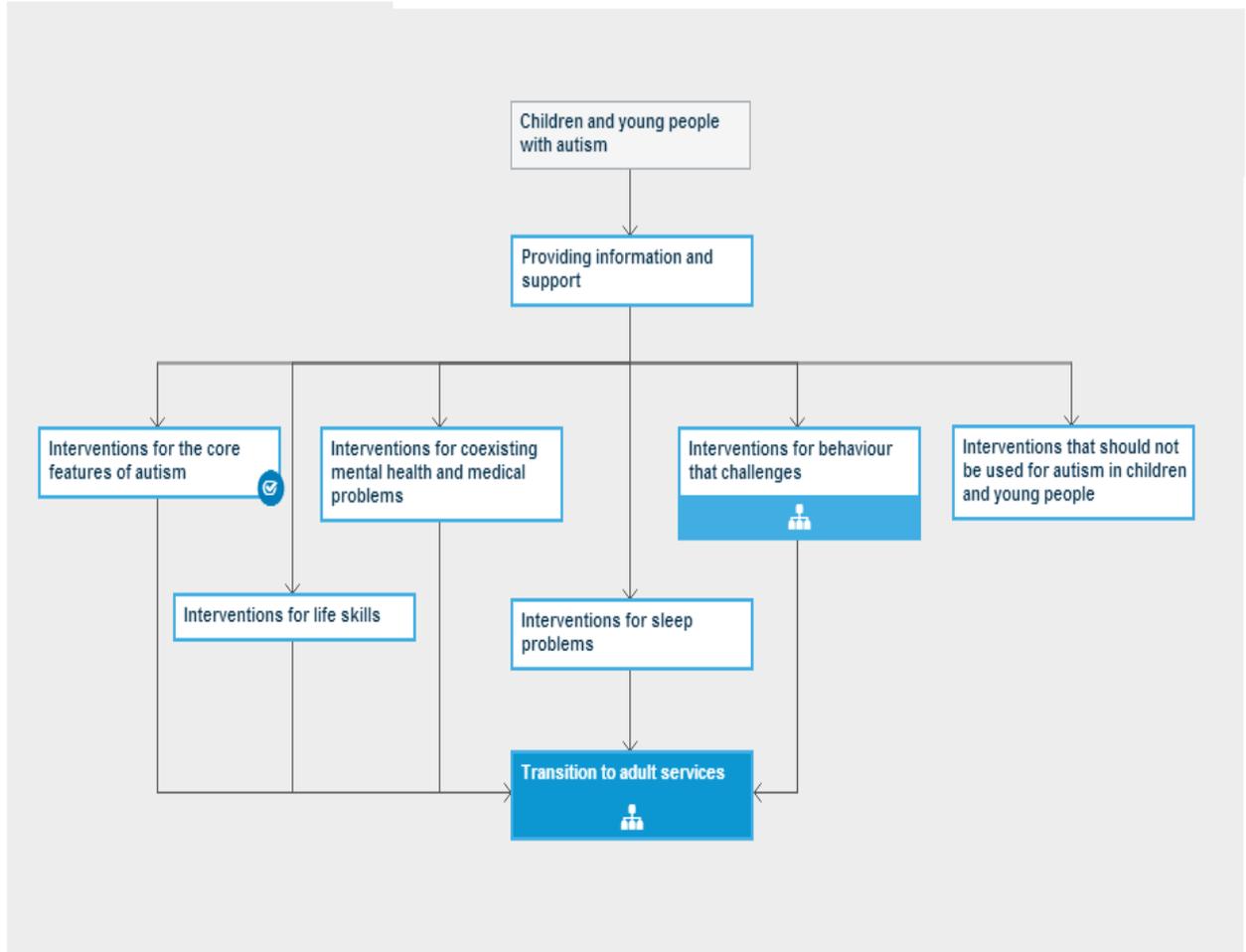
The autism diagnostic assessment for children and young people



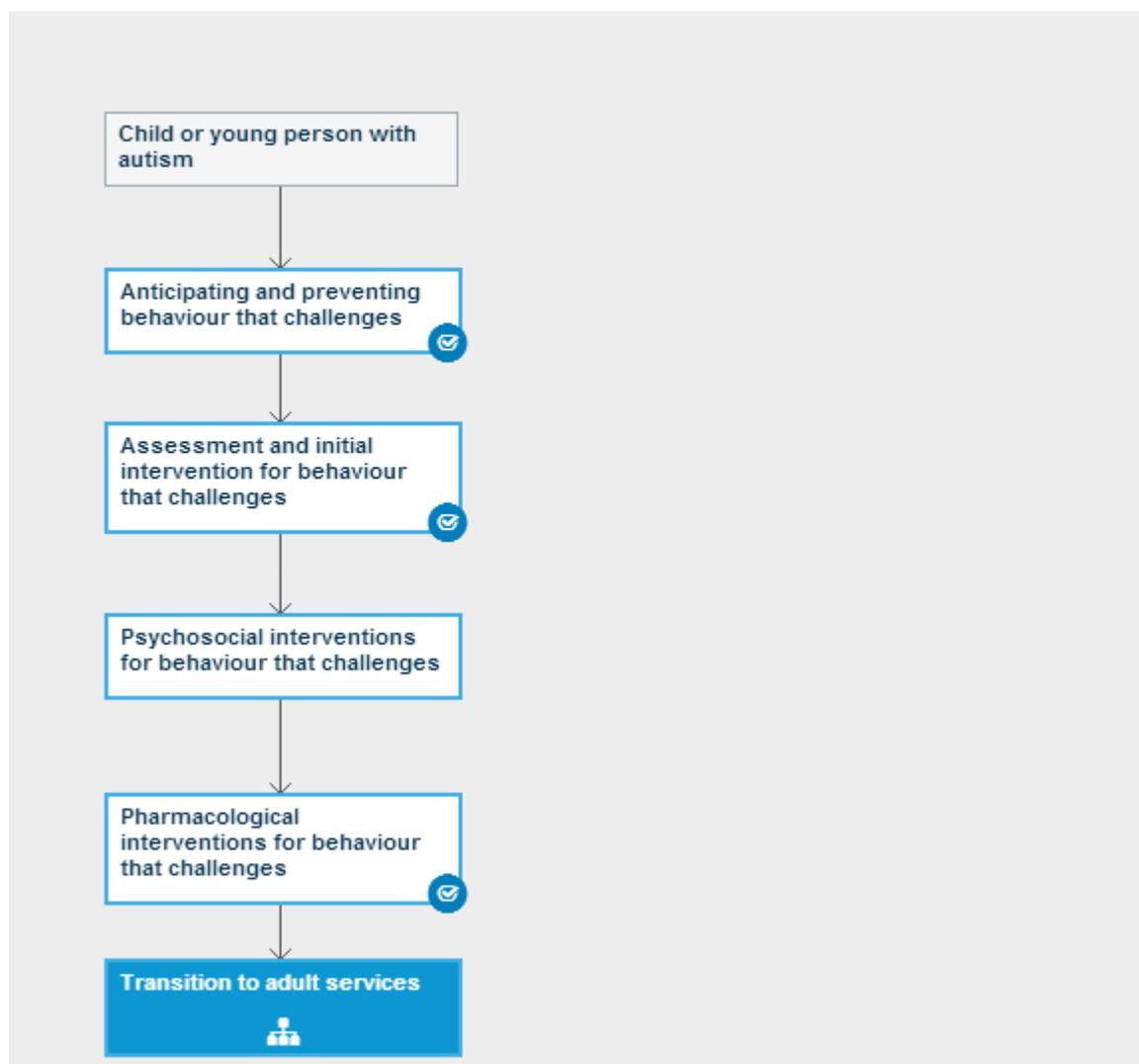
Diagnosing autism in children and young people



Management and support in children and young people with autism

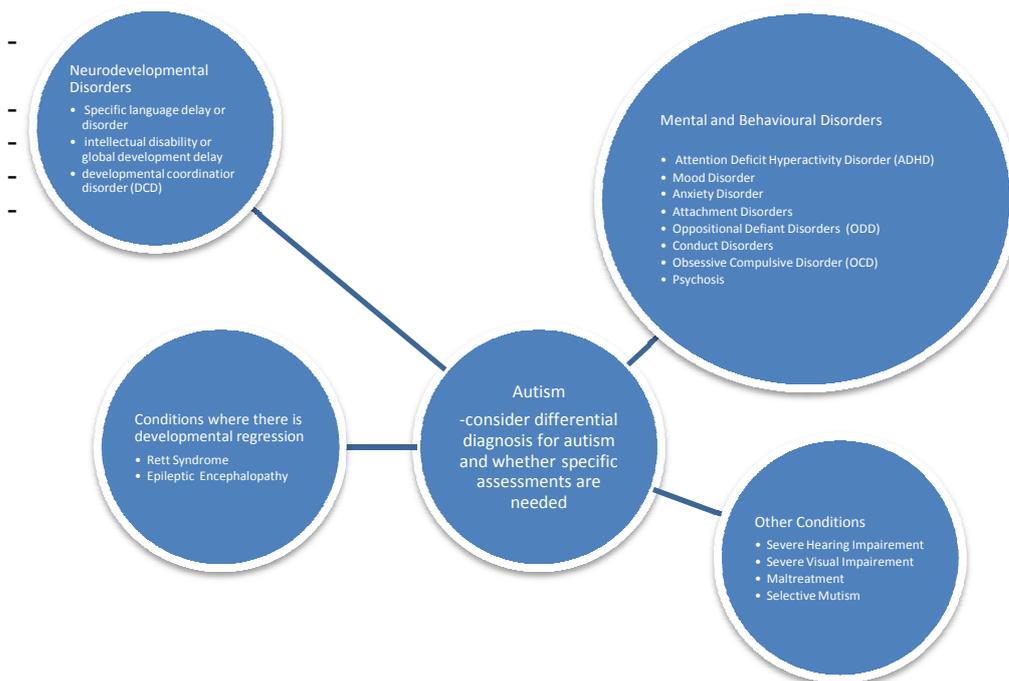


Interventions for behaviour that challenges in children and young people with autism



What should be included in an Autism Diagnostic Assessment

- Detailed questions about parent's or carer's concerns and, if appropriate, the child's or young person's concerns
- Details of the child's or young person's experiences of home life, education and social care
- A developmental history, focusing on developmental and behavioural features consistent with ICD-10 or DSM-IV criteria (consider using an autism-specific tool to gather this information)
- Assessment (through interaction with and observation of the child or young person) of social and communication skills and behaviours, focusing on features consistent with ICD-10 or DSM-IV criteria (consider using an autism-specific tool to gather this information)
- A medical history, including prenatal, perinatal and family history, and past and current health conditions
- A physical examination
- Consideration of the differential diagnosis



- Systematic assessment for conditions that may coexist with autism
- Development of a profile of the child's or young person's strengths, skills, impairments and needs that can be used to create a needs-based management plan, taking into account family and educational context
- Communication of assessment findings to the parent or carer and, if appropriate, the child or young person.

The Guidance – Autism spectrum disorder in under 19s: recognition, referral and diagnosis (September 2011)

1.1 Local pathway for recognition, referral and diagnostic assessment of possible autism

1.1.1

A local autism multi-agency strategy group should be set up, with managerial, commissioner and clinical representation from child health and mental health services, education, social care, parent and carer service users, and the voluntary sector.

1.1.2

The local autism strategy group should appoint a lead professional to be responsible for the local autism pathway for recognition, referral and diagnosis of children and young people.

The aims of the group should include: improving early recognition of autism by raising awareness of the signs and symptoms of autism through multi-agency training (see tables 1–3 in appendix C) making sure the relevant professionals (healthcare, social care, education and voluntary sector) are aware of the local autism pathway and how to access diagnostic services supporting the smooth transition to adult services for young people going through the diagnostic pathway ensuring data collection and audit of the pathway takes place.

1.1.3

In each area a multidisciplinary group (the autism team) should be set up.

The core membership should include a:

- paediatrician and/or child and adolescent psychiatrist
- speech and language therapist
- Clinical and/or educational psychologist.

1.1.4

The autism team should either include or have regular access to the following professionals

if they are not already in the team:

- paediatrician or paediatric neurologist
- child and adolescent psychiatrist
- educational psychologist
- clinical psychologist
- Occupational therapist.

1.1.5

Consider including in the autism team (or arranging access for the team to) other relevant professionals who may be able to contribute to the autism diagnostic assessment.

For example, a specialist health visitor or nurse, specialist teacher or social worker

1.1.6

The autism team should have the skills and competencies to:

- carry out an autism diagnostic assessment
- Communicate with children and young people with suspected or known autism, and with their parents and carers, and sensitively share the diagnosis with them.

1.1.7

Autism team members should:

- provide advice to professionals about whether to refer children and young people for autism diagnostic assessments
- decide on the assessment needs of those referred or when referral to another service will be needed
- carry out the autism diagnostic assessment
- share the outcome of the autism diagnostic assessment with parents and carers, and with children and young people if appropriate
- with parent or carer consent and, if appropriate, the consent of the child or young person, share information from the autism diagnostic assessment directly with relevant services, for example through a school visit by an autism team member
- Offer information to children, young people and parents and carers about appropriate services and support.

1.1.8

Provide a single point of referral for access to the autism team.

1.1.9

The autism team should either have the skills (or have access to professionals that have the skills) needed to carry out an autism diagnostic assessment, for children and young people with special circumstances including:

- coexisting conditions such as severe visual and hearing impairments, motor disorders including cerebral palsy, severe intellectual disability, complex language disorders or complex mental health disorders
- Looked-after children and young people.

1.1.10

If young people present at the time of transition to adult services, the autism team should consider carrying out the autism diagnostic assessment jointly with the adult autism team, regardless of the young person's intellectual ability.

1.2 Recognising children and young people with possible autism

1.2.1

Consider the possibility of autism if there are concerns about development or behaviour, but be aware that there may be other explanations for individual signs and symptoms.

1.2.2

Always take parents' or carers' concerns and, if appropriate, the child's or young person's concerns, about behaviour or development seriously, even if these are not shared by others.

1.2.3

When considering the possibility of autism and whether to refer a child or young person to the autism team, be critical about your professional competence and seek advice from a colleague if in doubt about the next step.

1.2.4

To help identify the signs and symptoms of possible autism, use tables 1–3 (see appendix C). Do not rule out autism if the exact features described in the tables are not evident; they should be used for guidance, but do not include all possible manifestations of autism.

1.2.5

When considering the possibility of autism, be aware that:

- signs and symptoms should be seen in the context of the child's or young person's overall development
- signs and symptoms will not always have been recognised by parents, carers, children or young people themselves or by other professionals
- when older children or young people present for the first time with possible autism, signs or symptoms may have previously been masked by the child or young person's coping mechanisms and/or a supportive environment
- it is necessary to take account of cultural variation, but do not assume that language delay is accounted for because English is not the family's first language or by early hearing difficulties
- autism may be missed in children or young people with an intellectual disability
- autism may be missed in children or young people who are verbally able
- autism may be under-diagnosed in girls
- important information about early development may not be readily available for some children and young people, for example looked-after children and those in the criminal justice system
- Signs and symptoms may not be accounted for by disruptive home experiences or parental or carer mental or physical illness.

1.2.6

When considering the possibility of autism, ask about the child or young person's use and understanding of their first language.

1.2.7

Do not rule out autism because of:

- good eye contact, smiling and showing affection to family members
- reported pretend play or normal language milestones
- difficulties appearing to resolve after a needs-based intervention (such as a supportive structured learning environment)
- A previous assessment that concluded that there was no autism, if new information becomes available.

1.2.8

Discuss developmental or behavioural concerns about a child or young person with parents or carers, and the child or young person themselves if appropriate. Discuss sensitively the possible causes, which may include autism, emphasising that there may be many explanations for the child's or young person's behaviour.

1.2.9

Be aware that if parents or carers or the child or young person themselves have not suspected a developmental or behavioural condition, raising the possibility may cause distress, and that:

- it may take time for them to come to terms with the concern
- they may not share the concern

1.2.10

Take time to listen to parents or carers and, if appropriate, the child or young person, to discuss concerns and agree any actions to follow including referral

1.3 Referring children and young people to the autism team

1.3.1

Refer children younger than 3 years to the autism team if there is regression in language or social skills.

1.3.2

Refer first to a paediatrician or paediatric neurologist (who can refer to the autism team if necessary) children and young people:

- older than 3 years with regression in language
- Of any age with regression in motor skills.

1.3.3

Consider referring children and young people to the autism team if you are concerned about possible autism on the basis of reported or observed signs and/or symptoms (see tables 1–3 in appendix C).

Take account of:

- the severity and duration of the signs and/or symptoms
- the extent to which the signs and/or symptoms are present across different settings (for example, home and school)
- the impact of the signs and/or symptoms on the child or young person and on their family
- the level of parental or carer concern and, if appropriate, the concerns of the child or young person
- factors associated with an increased prevalence of autism (see box 1)
- The likelihood of an alternative diagnosis.

Box 1 Factors associated with an increased prevalence of autism

A sibling with autism

Birth defects associated with central nervous system malformation and/or dysfunction, including cerebral palsy

Gestational age less than 35 weeks

Parental schizophrenia-like psychosis or affective disorder

Maternal use of sodium valproate in pregnancy

Intellectual disability

Neonatal encephalopathy or epileptic encephalopathy, including infantile spasms

Chromosomal disorders such as Down's syndrome

Genetic disorders such as fragile X

Muscular dystrophy

Neurofibromatosis

Tuberous sclerosis

1.3.4

If you have concerns about development or behaviour but are not sure whether the signs and/or symptoms suggest autism, consider:

- consulting a member of the autism team who can provide advice to help you decide if a referral to the autism team is necessary
- Referring to another service. That service can then refer to the autism team if necessary.

1.3.5

Be aware that tools to identify children and young people with an increased likelihood of autism may be useful in gathering information about signs and symptoms of autism in a structured way but are not essential and should not be used to make or rule out a diagnosis of autism.

Also be aware that:

- a positive score on tools to identify an increased likelihood of autism may support a decision to refer but can also be for reasons other than autism
- a negative score does not rule out autism.

1.3.6

When referring children and young people to the autism team, include in the referral letter the following information:

- reported information from parents, carers and professionals about signs and/or symptoms of concern
- Your own observations of the signs and/or symptoms.

1.3.7

When referring children and young people to the autism team, include in the referral letter the following information, if available:

- antenatal and perinatal history
- developmental milestones
- factors associated with an increased prevalence of autism (see box 1)
- relevant medical history and investigations
- Information from previous assessments.

1.3.8

Explain to parents or carers and, if appropriate, the child or young person, what will happen on referral to the autism team or another service.

1.3.9

If you do not think concerns are sufficient to prompt a referral, consider a period of watchful waiting. If you remain concerned about autism, reconsider your referral decision.

1.3.10

If the parents or carers or if appropriate, the child or young person, prefer not to be referred to the autism team, consider a period of watchful waiting. If you remain concerned about autism, reconsider referral.

1.3.11

If a concern about possible autism has been raised but there are no signs, symptoms or other reasons to suspect autism, use professional judgment to decide what to do next.

1.4 After referral to the autism team

1.4.1

When a child or young person is referred to the autism team, at least one member of the autism team should consider whether to carry out:

- an autism diagnostic assessment and/or
- An alternative assessment.

1.4.2

Carry out an autism diagnostic assessment if there is regression in language or social skills in a child younger than 3 years.

1.4.3

Refer first to a paediatrician or paediatric neurologist (if this has not already happened) children or young people:

- older than 3 years with regression in language
- Of any age with regression in motor skills

The paediatrician or paediatric neurologist can refer back to the autism team if necessary.

1.4.4

When deciding whether to carry out an autism diagnostic assessment, take account of the following (unless the child is under 3 years and has regression in language or social skills – see recommendation 1.4.2):

- the severity and duration of the signs and/or symptoms
- the extent to which the signs and/or symptoms are present across different settings (for example, home and school)
- the impact of the signs and/or symptoms on the child or young person and on their family or carer
- the level of parental or carer concern, and if appropriate the concerns of the child or young person
- factors associated with an increased prevalence of autism (see box 1)
- The likelihood of an alternative diagnosis.

1.4.5

If there is insufficient information to decide whether an autism diagnostic assessment is needed, gather any available information from healthcare professionals. With consent from parents or carers and, if appropriate, the child or young person, seek information from schools or other agencies.

1.4.6

If there is uncertainty about whether an autism diagnostic assessment is needed after information has been gathered, offer a consultation to gather information directly from the child or young person and their family or carers.

1.4.7

Once it has been decided to carry out an autism diagnostic assessment, with consent from parents or carers (and the child or young person if appropriate):

- seek a report from the pre-school or school if one has not already been made available
- Gather any additional health or social care information, including results from hearing and vision assessments.

1.4.8 Avoid repeated information gathering and assessments by efficient communication between professionals and agencies.

1.5 Autism diagnostic assessment for children and young people

1.5.1

Start the autism diagnostic assessment within 3 months of the referral to the autism team.

1.5.2

A case coordinator in the autism team should be identified for every child or young person who is to have an autism diagnostic assessment.

1.5.3

The autism case coordinator should:

- act as a single point of contact for the parents or carers and, if appropriate, the child or young person being assessed, through whom they can communicate with the rest of the autism team
- keep parents or carers and, if appropriate, the child or young person, up-to-date about the likely time and sequence of assessments
- arrange the provision of information and support for parents, carers, children and young people as directed by the autism team
- Gather information relevant to the autism diagnostic assessment (see recommendation 1.4.7).

1.5.4

Discuss with the parents or carers and, if appropriate, the child or young person, how information should be shared throughout the autism diagnostic assessment, including communicating the outcome of the assessment. Take into account, for example, the child or young person's age and ability to understand.

1.5.5

Include in every autism diagnostic assessment:

- detailed questions about parent's or carer's concerns and, if appropriate, the child's or young person's concerns
- details of the child's or young person's experiences of home life, education and social care
- a developmental history, focusing on developmental and behavioural features consistent with ICD-10 or DSM-IV criteria (consider using an autism-specific tool to gather this information)
- assessment (through interaction with and observation of the child or young person) of social and communication skills and behaviours, focusing on features consistent with ICD-10 or DSM-IV criteria (consider using an autism-specific tool to gather this information)
- a medical history, including prenatal, perinatal and family history, and past and current health conditions
- a physical examination
- consideration of the differential diagnosis (see recommendation 1.5.7)
- systematic assessment for conditions that may coexist with autism (see recommendation 1.5.15)
- Development of a profile of the child's or young person's strengths, skills, impairments and needs that can be used to create a needs-based management plan, taking into account family and educational context.
- Communication of assessment findings to the parent or carer and, if appropriate, the child or young person.

1.5.6

Perform a general physical examination and look specifically for:

- skin stigmata of neurofibromatosis or tuberous sclerosis using a Wood's light
- signs of injury, for example self-harm or child maltreatment
- Congenital anomalies and dysmorphic features including macrocephaly or microcephaly.

1.5.7

Consider the following differential diagnoses for autism and whether specific assessments are needed to help interpret the autism history and observations:

Neurodevelopmental disorders:

- specific language delay or disorder
- intellectual disability or global developmental delay
- Developmental coordination disorder (DCD).

Mental and behavioural disorders:

- attention deficit hyperactivity disorder (ADHD)
- mood disorder
- anxiety disorder
- attachment disorders
- oppositional defiant disorder (ODD)
- conduct disorder
- obsessive compulsive disorder (OCD)
- Psychosis.

Conditions in which there is developmental regression:

- Rett syndrome
- Epileptic encephalopathy.

Other conditions:

- severe hearing impairment
- severe visual impairment
- maltreatment
- Selective mutism.

1.5.8

Consider which assessments are needed to construct a profile for each child or young person, for example:

- intellectual ability and learning style
- academic skills
- speech, language and communication
- fine and gross motor skills
- adaptive behaviour (including self-help skills)
- mental and emotional health (including self-esteem)
- physical health and nutrition
- sensory sensitivities
- behaviour likely to affect day-to-day functioning and social participation
- Socialisation skills.

1.5.9

If there are discrepancies during the autism diagnostic assessment between reported signs or symptoms and the findings of the autism observation in the clinical setting, consider: gathering additional information from other sources and/or carrying out further autism-specific observations in different settings, such as the school, nursery, other social setting or at home.

1.5.10

Use information from all sources, together with clinical judgment, to diagnose autism based on ICD-10 or DSM-IV criteria.

1.5.11

Do not rely on any autism-specific diagnostic tool alone to diagnose autism.

1.5.12

Be aware that in some children and young people there may be uncertainty about the diagnosis of autism, particularly in:

- children younger than 24 months
- children or young people with a developmental age of less than 18 months
- children or young people for whom there is a lack of available information about their early life (for example some looked-after or adopted children)
- older teenagers
- Children or young people with a complex coexisting mental health disorder (for example ADHD, conduct disorder, a possible attachment disorder), sensory impairment (for example severe hearing or visual impairment), or a motor disorder such as cerebral palsy.

1.5.13

Be aware that some children and young people will have features of behaviour that are seen in the autism spectrum but do not reach the ICD-10 or DSM-IV diagnostic criteria for definitive diagnosis. Based on their profile, consider referring to appropriate services.

1.5.14

If the outcome of the autism diagnostic assessment clearly indicates that the child or young person does not have autism, consider referring them to appropriate services based on their profile.

1.5.15

Consider whether the child or young person may have any of the following as a coexisting condition, and if suspected carry out appropriate assessments and referrals:

- Mental and behaviour problems and disorders:
 - ADHD
 - anxiety disorders and phobias
 - mood disorders
 - oppositional defiant behaviour
 - tics or Tourettes syndrome
 - OCD
 - Self-injurious behaviour.
- Neurodevelopmental problems and disorders:
 - global delay or intellectual disability
 - motor coordination problems or DCD
 - academic learning problems, for example in literacy or numeracy
 - speech and language disorder.
- Medical or genetic problems and disorders:
 - epilepsy and epileptic encephalopathy
 - chromosome disorders
 - genetic abnormalities, including fragile X
 - tuberous sclerosis
 - muscular dystrophy
 - Neurofibromatosis.
- Functional problems and disorders:
 - feeding problems, including restricted diets
 - urinary incontinence or enuresis
 - constipation, altered bowel habit, faecal incontinence or encopresis
 - sleep disturbances
 - vision or hearing impairment

1.5.16

Be aware that in children and young people with communication difficulties it may be difficult to recognise functional problems or mental health problems

1.6 After the autism diagnostic assessment

1.6.1

If there is uncertainty after the autism diagnostic assessment about the diagnosis, consider keeping the child or young person under review, taking into account any new information.

1.6.2

If any of the following apply after assessment, consider obtaining a second opinion (including referral to a specialised tertiary autism team if necessary):

- continued uncertainty about the diagnosis
- disagreement about the diagnosis within the autism team
- disagreement with parents or carers or, if appropriate, the child or young person, about the diagnosis
- a lack of local access to particular skills and competencies needed to reach a diagnosis in a child or young person who has a complex coexisting condition, such as a severe sensory or motor impairment or mental health problem
- a lack of response as expected to any therapeutic interventions provided to the child or young person.

1.6.3

During the autism diagnostic assessment, consider any potential risk of harm to, and from, the child or young person and take appropriate action.

1.7 Medical investigations

1.7.1

Do not routinely perform any medical investigations as part of an autism diagnostic assessment, but consider the following in individual circumstances and based on physical examination, clinical judgment and the child or young person's profile:

- genetic tests, as recommended by your regional genetics centre,
- if there are specific dysmorphic features, congenital anomalies and/or evidence of intellectual disability
- electroencephalography if there is suspicion of epilepsy

1.8 Communicating the results from the autism diagnostic assessment

1.8.1

After the autism diagnostic assessment discuss the findings, (including the profile, sensitively, in person and without delay with the parents or carers and, if appropriate, the child or young person). Explain the basis of conclusions even if the diagnosis of autism was not reached.

1.8.2

Use recognised good practice when sharing a diagnosis with parents, carers, children and young people.

1.8.3

For children and young people with a diagnosis of autism, discuss and share information with parents or carers and, if appropriate, the child or young person, to explain:

- what autism is
- how autism is likely to affect the child or young person's development and function

1.8.4

Provide parents or carers and, if appropriate, the child or young person, with a written report of the autism diagnostic assessment. This should explain the findings of the assessment and the reasons for the conclusions drawn.

1.8.5

Share information, including the written report of the diagnostic assessment, with the GP

1.8.6

With parental or carer consent and, if appropriate, the consent of the child or young person, share information with key professionals involved in the child's or young person's care, including those in education and social care.

1.8.7

With parental or carer consent and, if appropriate, the consent of the child or young person, make the profile available to professionals in education (for example, through a school visit by a member of the autism team) and, if appropriate, social care. This is so it can contribute to the child or young person's individual education plan and needs-based management plan.

1.8.8

For children and young people with a diagnosis of autism, offer a follow-up appointment with an appropriate member of the autism team within 6 weeks of the end of the autism assessment for further discussion (for example about the conclusions of the assessment and the implications for the child or young person).

1.8.9

For children and young people with a diagnosis of autism, discuss with parents or carers the risk of autism occurring in siblings and future children.

1.9 Information and support for families and carers

1.9.1

Provide individual information on support available locally for parents, carers, children and young people with autism, according to the family's needs.

ASD Helping Hands is a local support organisation which covers this aspect of the NICE guidelines

- we offer opportunities to meet other families with experience of autism
- our entire team have hands on experience of autism
- We offer information about specific courses for parents and carers
- We provide advice on welfare benefits
- We provide information on educational support and social care
- We help prepare for the future including transition to adult services

The Guidance (Recommendations) – Autism spectrum disorder in under 19s: support and management

1.1 General principles of care

Access to health and social care services

1.1.1

Ensure that all children and young people with autism have full access to health and social care services, including mental health services, regardless of their intellectual ability or any coexisting diagnosis.

Organisation and delivery of services

1.1.2

The overall configuration and development of local services (including health, mental health, learning disability, education and social care services) for children and young people with autism, should be coordinated by a local autism multi-agency strategy group (for people with autism of all ages) in line with Autism in children and young people (covering identification and diagnosis) (NICE clinical guideline 128) and Autism in adults (NICE clinical guideline 142).

1.1.3

The assessment, management and coordination of care for children and young people with autism should be provided through local specialist community-based multidisciplinary teams ('local autism teams') which should include professionals from health, mental health, learning disability, education and social care services in line with Autism in children and young people (covering identification and diagnosis) (NICE clinical guideline 128) and Autism in adults (NICE clinical guideline 142).

1.1.4

Local autism teams should ensure that every child or young person diagnosed with autism has a case manager or key worker to manage and coordinate treatment, care, support and transition to adult care in line with Autism in children and young people (covering identification and diagnosis) (NICE clinical guideline 128).

1.1.5

Local autism teams should provide (or organise) the interventions and care recommended in this guideline for children and young people with autism who have particular needs, including:

- looked-after children and young people
- those from immigrant groups
- those with regression in skills
- those with coexisting conditions such as:
 - severe visual and hearing impairments
 - other medical problems including epilepsy or sleep and elimination problems
 - motor disorders including cerebral palsy
 - intellectual disability
 - severe communication impairment, including lack of spoken language, or complex language disorders
- Mental health problems.

1.1.6

Local autism teams should have a key role in the delivery and coordination of:

- specialist care and interventions for children and young people with autism, including those living in specialist residential accommodation
- advice, training and support for other health and social care professionals and staff (including in residential and community settings) who may be involved in the care of children and young people with autism
- advice and interventions to promote functional adaptive skills including communication and daily living skills
- assessing and managing behaviour that challenges
- assessing and managing coexisting conditions
- reassessing needs throughout childhood and adolescence, taking particular account of transition to adult services
- supporting access to leisure and enjoyable activities
- supporting access to and maintaining contact with educational, housing and employment services
- providing support for families (including siblings) and carers, including offering short breaks and other respite care
- producing local protocols for:
 - information sharing, communication and collaborative working among healthcare, education and social care services, including arrangements for transition to adult services
- Shared care arrangements with primary care providers and ensuring that clear lines of communication between primary and secondary care are maintained.

1.1.7

Refer children and young people with autism to a regional or national autism service if there is a lack of: local skills and competencies needed to provide interventions and care for a child or young person with a complex coexisting condition, such as a severe sensory or motor impairment or mental health problem, or response to the therapeutic interventions provided by the local autism team.

Knowledge and competence of health and social care professionals

1.1.8

Health and social care professionals working with children and young people with autism in any setting should receive training in autism awareness and skills in managing autism, which should include:

- the nature and course of autism
- the nature and course of behaviour that challenges in children and young people with autism
- recognition of common coexisting conditions, including:
 - mental health problems such as anxiety and depression
 - physical health problems such as epilepsy
 - sleep problems
 - other neurodevelopmental conditions such as attention deficit hyperactivity disorder (ADHD)
- the importance of key transition points, such as changing schools or health or social care services
- the child or young person's experience of autism and its impact on them
- the impact of autism on the family (including siblings) or carers
- the impact of the social and physical environment on the child or young person

- how to assess risk (including self-harm, harm to others, self-neglect, breakdown of family or residential support, exploitation or abuse by others) and develop a risk management plan
- the changing needs that arise with puberty (including the child or young person's understanding of intimate relationships and related problems that may occur, for example, misunderstanding the behaviour of others)
- how to provide individualised care and support and ensure a consistent approach is used across all settings
- Skills for communicating with a child or young person with autism.

Making adjustments to the social and physical environment and processes of care

1.1.9

Take into account the physical environment in which children and young people with autism are supported and cared for. Minimise any negative impact by:

- providing visual supports, for example, words, pictures or symbols that are meaningful for the child or young person
- making reasonable adjustments or adaptations to the amount of personal space given
- Considering individual sensory sensitivities to lighting, noise levels and the colour of walls and furnishings

1.1.10

Make adjustments or adaptations to the processes of health or social care, for example, arranging appointments at the beginning or end of the day to minimise waiting time, or providing single rooms for children and young people who may need a general anaesthetic in hospital (for example, for dental treatment).

Information and involvement in decision-making

1.1.11

Provide children and young people with autism, and their families and carers, with information about autism and its management and the support available on an ongoing basis, suitable for the child or young person's needs and developmental level. This may include:

- contact details for local and national organisations that can provide:
- support and an opportunity to meet other people, including families or carers, with experience of autism
- information on courses about autism
- advice on welfare benefits, rights and entitlements
- information about educational and social support and leisure activities
- information about services and treatments available
- information to help prepare for the future, for example, transition to adult services

1.1.12

Make arrangements to support children and young people with autism and their family and carers during times of increased need, including major life changes such as puberty, starting or changing schools, or the birth of a sibling.

1.1.13

Explore with children and young people with autism, and their families and carers, whether they want to be involved in shared decision-making and continue to explore these issues at regular intervals. If children and young people express interest, offer a collaborative approach to treatment and care that takes their preferences into account.

1.2 Families and carers

1.2.1

Offer all families (including siblings) and carers verbal and written information about their right to:

- short breaks and other respite care
- a formal carer's assessment of their own physical and mental health needs, and how to access these

1.2.2

Offer families (including siblings) and carers an assessment of their own needs, including whether they have:

- personal, social and emotional support
- practical support in their caring role, including short breaks and emergency plans
- a plan for future care for the child or young person, including transition to adult services

1.2.3

When the needs of families and carers have been identified, discuss help available locally and, taking into account their preferences, offer information, advice, training and support, especially if they:

- need help with the personal, social or emotional care of the child or young person, including age-related needs such as self-care, relationships or sexuality
- are involved in the delivery of an intervention for the child or young person in collaboration with health and social care professionals

1.3 Specific interventions for the core features of autism

Psychosocial interventions

1.3.1

Consider a specific social-communication intervention for the core features of autism in children and young people that includes play-based strategies with parents, carers and teachers to increase joint attention, engagement and reciprocal communication in the child or young person.

Strategies should:

- be adjusted to the child or young person's developmental level
- aim to increase the parents', carers', teachers' or peers' understanding of, and sensitivity and responsiveness to, the child or young person's patterns of communication and interaction
- include techniques of therapist modelling and video-interaction feedback
- Include techniques to expand the child or young person's communication, interactive play and social routines

The intervention should be delivered by a trained professional. For pre-school children consider parent, carer or teacher mediation.

For school-aged children consider peer mediation.

Pharmacological and dietary interventions

1.3.2

Do not use the following interventions for the management of core features of autism in children and young people:

Antipsychotics

Antidepressants

Anticonvulsants

Exclusion diets (such as gluten- or casein-free diets).

1.4 Interventions for behaviour that challenges

Anticipating and preventing behaviour that challenges

1.4.1

Assess factors that may increase the risk of behaviour that challenges in routine assessment and care planning in children and young people with autism, including:

- impairments in communication that may result in difficulty understanding situations or in expressing needs and wishes
- coexisting physical disorders, such as pain or gastrointestinal disorders
- coexisting mental health problems such as anxiety or depression and other neurodevelopmental conditions such as ADHD
- the physical environment, such as lighting and noise levels
- the social environment, including home, school and leisure activities
- changes to routines or personal circumstances
- developmental change, including puberty
- exploitation or abuse by others
- inadvertent reinforcement of behaviour that challenges
- the absence of predictability and structure

1.4.2

Develop a care plan with the child or young person and their families or carers that outlines the steps needed to address the factors that may provoke behaviour that challenges, including:

- treatment, for example, for coexisting physical, mental health and behavioural problems
- support, for example, for families or carers
- necessary adjustments, for example, by increasing structure and minimising unpredictability

Assessment and initial intervention for behaviour that challenges

1.4.3

If a child or young person's behaviour becomes challenging, reassess factors identified in the care plan and assess for any new factors that could provoke the behaviour.

1.4.4

Offer the following to address factors that may trigger or maintain behaviour that challenges:

- treatment for physical disorders, or coexisting mental health and behavioural problems
- interventions aimed at changing the environment, such as:
- providing advice to families and carers
- making adjustments or adaptations to the physical surroundings
(see [recommendation 1.1.9](#))

1.4.5

If behaviour remains challenging despite attempts to address the underlying possible causes, consult senior colleagues and undertake a multidisciplinary review.

1.4.6

At the multidisciplinary review, take into account the following when choosing an intervention for behaviour that challenges:

- the nature, severity and impact of the behaviour
- the child or young person's physical and communication needs and capabilities
- the environment
- the support and training that families, carers or staff may need to implement the intervention effectively
- the preferences of the child or young person and the family or carers
- the child or young person's experience of, and response to, previous interventions

Psychosocial interventions for behaviour that challenges

1.4.7

If no coexisting mental health or behavioural problem, physical disorder or environmental problem has been identified as triggering or maintaining the behaviour that challenges, offer the child or young person a psychosocial intervention (informed by a functional assessment of behaviour) as a first-line treatment.

1.4.8

The functional assessment should identify:

- factors that appear to trigger the behaviour
- patterns of behaviour
- the needs that the child or young person is attempting to meet by performing the behaviour
- the consequences of the behaviour (that is, the reinforcement received as a result of the behaviour)

1.4.9

Psychosocial interventions for behaviour that challenges should include:

- clearly identified target behaviour
- a focus on outcomes that are linked to quality of life
- assessment and modification of environmental factors that may contribute to initiating or maintaining the behaviour
- a clearly defined intervention strategy that takes into account the developmental level and coexisting problems of the child or young person
- a specified timescale to meet intervention goals (to promote modification of intervention strategies that do not lead to change within a specified time)
- a systematic measure of the target behaviour taken before and after the intervention to ascertain whether the agreed outcomes are being met
- consistent application in all areas of the child or young person's environment (for example, at home and at school)
- agreement among parents, carers and professionals in all settings about how to implement the intervention

Pharmacological interventions for behaviour that challenges

1.4.10

Consider antipsychotic medication for managing behaviour that challenges in children and young people with autism when psychosocial or other interventions are insufficient or could not be delivered because of the severity of the behaviour. Antipsychotic medication should be initially prescribed and monitored by a paediatrician or psychiatrist who should:

- identify the target behaviour
- decide on an appropriate measure to monitor effectiveness, including frequency and severity of the behaviour and a measure of global impact
- review the effectiveness and any side effects of the medication after 3–4 weeks
- stop treatment if there is no indication of a clinically important response at 6 weeks

1.4.11

If antipsychotic medication is prescribed:

- start with a low dose
- use the minimum effective dose needed
- regularly review the benefits of the antipsychotic medication and any adverse events

1.4.12

When choosing antipsychotic medication, take into account side effects, acquisition costs, the child or young person's preference (or that of their parent or carer where appropriate) and response to previous treatment with an antipsychotic.

1.4.13

When prescribing is transferred to primary or community care, the specialist should give clear guidance to the practitioner who will be responsible for continued prescribing about:

- the selection of target behaviours
- monitoring of beneficial and side effects
- the potential for minimally effective dosing
- the proposed duration of treatment
- plans for stopping treatment

Psychological therapy

If your behaviour continues to cause problems for you and other people, and there is no obvious cause for it, you should be offered a psychological therapy to help to change the behaviour. You and your parents or carers should have a say in the choice of treatment you are offered. It should be clear how long the therapy will last and how it will be judged to have worked.

Medication

If psychological therapy does not help, or the behaviour is severe, you may be offered medication called 'antipsychotic medication'. This should only be offered by a paediatrician or psychiatrist who should talk to you about which medication suits you best and whether you have taken similar medication before. You should have a check-up after 3–4 weeks and the medication should be stopped after 6 weeks if it is not helping

Some care and management may not be suitable for you, depending on your exact circumstances. If you think that your care or management does not match this advice, talk to your autism team.

Questions about behaviour that challenges

- What is causing me to behave like his? What could help me to behave in a different way?
- What does this type of therapy involve and how long does it last?
- How will this type of therapy help me?
- If you are offered medication:
- How long will I have to take the medication?
- What are the possible side effects of taking this medication?
- Might I have problems when I stop taking the medication?

1.5 Interventions for life skills

1.5.1 Offer children and young people with autism support in developing coping strategies and accessing community services, including developing skills to access public transport, employment and leisure facilities.

1.7 Interventions for coexisting problems

1.7.1

Offer psychosocial and pharmacological interventions for the management of coexisting mental health or medical problems in children and young people with autism in line with NICE guidance for children and young people, including:

- [Attention deficit hyperactivity disorder \(ADHD\)](#) (NICE clinical guideline 72)
- [Conduct disorders in children and young people](#) (NICE clinical guideline 158)
- [Constipation in children and young people](#) (NICE clinical guideline 99)
- [Depression in children and young people](#) (NICE clinical guideline 28)
- [Epilepsy](#) (NICE clinical guideline 137)
- [Obsessive-compulsive disorder \(OCD\) and body dysmorphic disorder \(BDD\)](#) (NICE clinical guideline 31)
- [Post-traumatic stress disorder \(PTSD\)](#) (NICE clinical guideline 26)

1.7.2

Consider the following for children and young people with autism and anxiety who have the verbal and cognitive ability to engage in a cognitive behavioural therapy (CBT) intervention:

- group CBT adjusted to the needs of children and young people with autism
- individual CBT for children and young people who find group-based activities difficult

1.7.3

Consider adapting the method of delivery of CBT for children and young people with autism and anxiety to include:

- emotion recognition training
- greater use of written and visual information and structured worksheets
- a more cognitively concrete and structured approach
- simplified cognitive activities, for example, multiple-choice worksheets
- involving a parent or carer to support the implementation of the intervention, for example, involving them in therapy sessions
- maintaining attention by offering regular breaks
- incorporating the child or young person's special interests into therapy if possible

Interventions for sleep problems

1.7.4 If a child or young person with autism develops a sleep problem offer an assessment that identifies:

- what the sleep problem is (for example, delay in falling asleep, frequent waking, unusual behaviours, breathing problems or sleepiness during the day)
- day and night sleep patterns, and any change to those patterns
- whether bedtime is regular
- what the sleep environment is like, for example:
 - the level of background noise
 - use of a blackout blind
 - a television or computer in the bedroom
- whether the child shares the room with someone
- presence of comorbidities especially those that feature hyperactivity or other behavioural problems
- levels of activity and exercise during the day
- possible physical illness or discomfort (for example, reflux, ear or toothache, constipation or eczema)
- effects of any medication
- any other individual factors thought to enhance or disturb sleep, such as emotional relationships or problems at school
- the impact of sleep and behavioural problems on parents or carers and other family members

1.7.5

If the child or young person with autism snores loudly, chokes or appears to stop breathing while sleeping, refer to a specialist to check for obstructive sleep apnoea.

1.7.6

Develop a sleep plan (this will often be a specific sleep behavioural intervention) with the parents or carers to help address the identified sleep problems and to establish a regular night-time sleep pattern. Ask the parents or carers to record the child or young person's sleep and wakefulness throughout the day and night over a 2-week period. Use this information to modify the sleep plan if necessary and review the plan regularly until a regular sleep pattern is established.

1.7.7

Do not use a pharmacological intervention to aid sleep unless:

- sleep problems persist despite following the sleep plan
- sleep problems are having a negative impact on the child or young person and their family or carers

If a pharmacological intervention is used to aid sleep it should:

- only be used following consultation with a specialist paediatrician or psychiatrist with expertise in the management of autism or paediatric sleep medicine
- be used in conjunction with non-pharmacological interventions
- be regularly reviewed to evaluate the ongoing need for a pharmacological intervention and to ensure that the benefits continue to outweigh the side effects and risks

1.7.8

If the sleep problems continue to impact on the child or young person or their parents or carers, consider:

- referral to a paediatric sleep specialist and
- Short breaks and other respite care for one night or more. Short breaks may need to be repeated regularly to ensure that parents or carers are adequately supported. Agree the frequency of breaks with them and record this in the care plan

1.8 Transition to adult services

1.8.1

Local autism teams should ensure that young people with autism who are receiving treatment and care from child and adolescent mental health services (CAMHS) or child health services are reassessed at around 14 years to establish the need for continuing treatment into adulthood.

1.8.2

If continuing treatment is necessary, make arrangements for a smooth transition to adult services and give information to the young person about the treatment and services they may need.

1.8.3

The timing of transition may vary locally and individually but should usually be completed by the time the young person is 18 years. Variations should be agreed by both child and adult services.

1.8.4

As part of the preparation for the transition to adult services, health and social care professionals should carry out a comprehensive assessment of the young person with autism.

1.8.5

The assessment should make best use of existing documentation about personal, educational, occupational, social and communication functioning, and should include assessment of any coexisting conditions, especially depression, anxiety, ADHD, obsessive-compulsive disorder (OCD) and global delay or intellectual disability in line with [Autism in adults](#) (NICE clinical guideline 142).

1.8.6

For young people aged 16 or older whose needs are complex or severe, use the care programme approach (CPA) in England, or care and treatment plans in Wales, as an aid to transfer between services.

1.8.7

Involve the young person in the planning and, where appropriate, their parents or carers.

1.8.8

Provide information about adult services to the young person, and their parents or carers, including their right to a social care assessment at age 18.

1.8.9

During transition to adult services, consider a formal meeting involving health and social care and other relevant professionals from child and adult services.

NICE Guidelines have issued some 'Do Not's for children and young people with Autism

- 1. Do not use antipsychotics for the management of core features of autism in children and young people**
- 2. Do not use antidepressants for the management of core features of autism in children and young people**
- 3. Do not use anticonvulsants for the management of core features of autism in children and young people**
- 4. Do not use exclusion diets (such as gluten or casein free diets) for the management of core features of autism in children and young people**
- 5. Do not use neurofeedback to manage speech and language problems in children and young people with autism**
- 6. Do not use auditory integration training to manage sleep problems in children and young people with autism**
- 7. Do not use omega-3 fatty acids to manage sleep problems in children and young people with autism**
- 8. Do not use secretin to manage autism in any context in children and young people**
- 9. Do not use chelation to manage autism in any context in children and young people**
- 10. Do not use hyperbaric oxygen therapy to manage autism in any context in children and young people**
- 11. Do not use a pharmacological intervention to aid sleep unless sleep problems persist despite following the sleep plan**
- 12. Do not use a pharmacological intervention to aid sleep unless sleep problems are having a negative impact on the child or young person and their family or carers**

How ASD Helping Hands can assist with the implementation of NICE guidelines

4.1 Training Professionals

SEN Training College – we as an organisation recognise the need to train professionals to recognise signs and symptoms of autism thus leading to earlier assessment of needs and earlier diagnosis among children and young people with suspected autism.

The courses we offer are

Level 1

Dyslexia
Dyspraxia

Level 2

ADHD
Dyslexia
Dyspraxia
Asperger Syndrome

Level 3

ADHD Awareness
Dyslexia Awareness
Dyspraxia Awareness

Level 4

Supporting the learning of learners with SEND

ADHD

- Awareness of ADHD Level 2
- Awareness of ADHD Level 3
- Supporting learners with Attention Deficit Hyperactivity Disorder Level 3

Autism

Award in Supporting Children & Young People with Autism Level 3 (QCF)

4.2 Gathering information in schools or nurseries

Because Autism is primarily characterised by difficulties in social reciprocity, social communication and social understanding, along with rigid and repetitive ways of thinking and behaving it is important to look at how the child or young person presents in social settings away from the home and immediate family. Nursery's or schools are the most obvious settings from which such information may be collected

ASD Helping Hands can assist to liaise with schools where parents feel there child or young person may have a diagnosis.

Recommendations

2.1 A key worker approach for children and young people with autism and their families

What is the value of a key worker approach (defined by protocol and delivered in addition to usual care) for children and young people with autism in terms of parental satisfaction, functioning and stress and child psychopathology?

Why this is important?

Autism is well characterised as a chronic disorder with lifelong disability in some individuals, yet the current health management structure is usually organised around single episodes of care. The theory and practice of management of chronic illness, as well as widely expressed service-user opinion, indicate that a chronic care model for the organisation of autism services could be appropriate and cost effective.

A key worker approach for children and young people with autism and their families should be formally evaluated in a randomised controlled trial (RCT) reporting short- and medium-term outcomes (including cost-effectiveness) with a follow-up of at least 6 months and again at 12 months. The outcomes (parental satisfaction, functioning and stress and child psychopathology) should be assessed by structured clinical interviews, parent- and self-reports using validated questionnaires and objective measures of behaviour. The study needs to be large enough to determine the presence of clinically important effects, and mediators and moderators (in particular the child or young person's age) should be investigated.

2.2 Managing behaviour that challenges in children and young people with autism

Is a group-based parent training intervention for parents or carers of children and young people with autism clinically and cost effective in reducing early and emerging behaviour that challenges in the short- and medium-term compared with treatment as usual?

Why this is important?

Behaviour that challenges is common in children and young people with autism but many are referred only when the behaviour has become severely impairing, they pose a threat to themselves or others, or everyday life has broken down. By this time, behavioural interventions may be difficult or impossible and antipsychotic medication is used despite it being symptomatic in its benefits, having long-term adverse effects and behavioural problems typically recurring after use.

A group-based parent training intervention (such as educating parents to identify triggers and patterns of reinforcement) should be evaluated using an RCT. Primary outcomes should be short- and medium-term reduction in behaviour that challenges. Secondary outcomes should include parental and sibling stress, quality of life and the child or young person's adaptive function. The medium-term use of medication should also be assessed. Cost effectiveness should encompass a wide range of services, such as additional educational support and social services, and health service use by families.

ASD Helping Hands has behaviour strategy packs to assist with this and will also incorporate challenging behaviour into parenting programmes specifically for parents and carers of children and young people with Autism

2.3 Managing sleep problems in children with autism

Is a sleep hygiene intervention or melatonin clinically and cost effective in the management of sleep onset, night waking and reduced total sleep in children (aged 4–10 years) with autism?

Why this is important?

Sleep problems are common in children and young people with autism and have a significant negative impact on them and their parents. However, studies of melatonin have used different groups and preparations of melatonin precluding meta-analysis.

The intervention should be evaluated in an RCT in 3 stages:

- (1) Recording sleep onset, night waking and total sleep time over 3 months using actigraphy and a parent-completed diary;
- (2) For those with a sleep problem, random allocation to sleep hygiene by booklet or professional contact;
- (3) For those with persistent sleep problems after 3 months, random allocation to prolonged-release melatonin or placebo; after a further 3 months, those on placebo would be offered melatonin.

It should report primary and secondary outcomes followed up at 12 months for all participants. Primary outcomes should include increased total sleep time and decreased night waking. Secondary outcomes should include improved sleep onset, a change in Aberrant Behaviour Checklist measures of behaviour that challenges, and improvement in parental stress index and satisfaction and the child's cognitive function.

2.4 Treating comorbid anxiety in children and young people with autism

What is the comparative clinical and cost effectiveness of pharmacological and psychosocial interventions for anxiety disorders in children and young people with autism?

Why this is important?

Early trials of CBT for anxiety in children and young people with autism have been promising but have methodological shortcomings. Furthermore, the common pharmacological approaches have not been evaluated in this population.

A parallel-arm RCT should compare pharmacological and psychosocial interventions with placebo in children and young people with autism and an anxiety disorder. Pharmacological treatment should be with a selective serotonin reuptake inhibitor (SSRI) and dosing should follow research in typically developing children but with the option of evaluating outcomes at lower doses.

The SSRI should be blinded with an identical placebo and an 'attention' or other psychosocial control group. The psychosocial intervention should be manualised and based on cognitive behavioural approaches shown to be effective in previous trials. The sample should cover the full age and intellectual range of children and young people and the size powered to deliver precise effect size estimates for both active arms.

Primary outcome measures should be reduction in anxiety symptoms by parent report. Secondary outcomes may include self- and teacher-report, blinded measures such as heart rate and skin conductance, patient satisfaction, changes in adaptive function, quality of life and disruptive behaviour. Adverse effects should be evaluated and an economic evaluation included.

2.5 Teacher-, parent- and peer-mediated psychosocial interventions in pre-school children with autism

Are comprehensive early interventions that combine multiple elements and are delivered by parents and teachers (for example, the Learning Experiences – an Alternative Program for Preschoolers and their Parents [LEAP] model) effective in managing the core symptoms of autism and coexisting difficulties (such as adaptive behaviour and developmental skills) in pre-school children?

Why this is important?

Many children with autism are diagnosed in the pre-school period when service provision is advice and support to parents and professionals in nursery or early years educational settings. There is evidence from one moderate-sized trial that adequately supervised comprehensive programmes can help manage the core symptoms of autism and coexisting difficulties. However, the quality of the trial was low.

The research programme should be in 4 stages:

1. Develop a manualised programme suitable to UK public service settings (health services, early year's education, and so on).
2. Test its feasibility and acceptability in pilot trials with blinded assessment of outcome.
3. Formally evaluate the outcomes on core symptoms of autism and coexisting difficulties in a large-scale trial, including health economic analysis.
4. Conduct a series of smaller trials to determine the elements, length and intensity required to ensure effectiveness of the programme, as well as longer-term outcomes.

Keep in touch

Find out more about how we can help you and your family, and how you can get involved with our work. Just fill in this form and post it back to us



Title
First Name
Surname
Address (line 1)
Address (line 2)
Address (line 3)
Town
Postcode
Telephone number
Mobile number
Email address

ASD Helping Hands would like to keep you informed about our services, upcoming news, events and fundraising activities. We will look after your data as set out in our privacy and data protection policy.

If you prefer not to receive information by post, please tick this box

If you prefer not to receive information by telephone, please tick this box

We'd like to keep in touch by email, if you are happy with this, please write your email address in the space provided above

What is the date of birth of the person you are contacting us about?

□□ / □□ / □□

Please return this form to:
Room 219 Breckland Business Centre
St Withburga Lane
Dereham
Norfolk
NR19 1FD

We would like to tailor our communication with you to ensure they are relevant to your interests.

What is your connection with autism?
(Please tick all that apply)

I am autistic

I am the parent/carer of someone on the Autistic Spectrum

Someone in my family is diagnosed with autism

I know someone who's autistic

I am a professional working in the field of autism

I have another connection with autism
Please Specify _____

I have no connection with Autism

“ASD Helping Hands will support all service users affected by an Autistic Spectrum Disorder (ASD) regardless of age or what stage of life they are at. We aim to offer guidance, practical advice and support whether you are personally affected or you are an associated family member, carer, friend or professional. We will actively champion the rights of all people affected by ASD’s and aim to make a positive difference to their lives while delivering a service that is accessible, reliable and trustworthy.”

The organisation is for all affected by the Autistic Spectrum, this covers a wide variety of difficulties. We believe that all families and individuals have the right to good quality information, support and guidance in order to promote empowerment to allow positive choices to be made, enabling access to the same opportunities as everybody.

Currently working across Norfolk and Suffolk

ASD Helping Hands

219 Breckland Business Centre
St Withburga Lane
Dereham
Norfolk
NR19 1FD

Autism Helpline: 01362 853018
Email: asdhelplinghands@gmail.com
Website: www.asdhelplinghands.org.uk

ASD Helping Hands is a voluntary organisation and relies on voluntary income to support its work, including the development of resources like this one for parents and carers

©ASD Helping Hands 2017